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“DISABILITY IS AN ART...”: DISABILITY AS DISCOURSE/COUNTER-DISCOURSE

by

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Bachelor of Arts
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Submitted in Partial Fulfillment of the Requirements

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DEDICATION

This work is dedicated to my mother, who said I could. And should.

ACKNOWLEDGEMENTS

A task as big as this requires a lot of people. To begin, my thesis committee: Dr. Heidi Rae Cooley, one of the most brilliant people I know and a fantastic mentor among mentors. Evan Meaney, who always indulged me, while also pushing me to be a better artist. No pun intended. A most brilliant “sous chef.” And of course, Dr. Mark Cooper, without whom I wouldn’t have a thesis committee to begin with, and whose insistence on “Normalcy” makes this thesis better. Thank you all.

At the risk of pontificating, I must also thank the Media Arts faculty (and instructors) at SVAD generally, but specifically Simon Tarr and Laura Kissel. The former for prodding me to apply to the MA program in Media Arts in the first place, and then, providing me (by way of offer) with my first paying job; and the latter for always being down to discuss disability, and for being such a conscious voice as such in the classroom.

ABSTRACT

This is a multipart thesis focused on the intersection between disability and art. What does it mean as an artist to engage the topic of disability? Relatedly, how do artists, art objects, and various aspects of culture contend with or confront disability? It is my contention that many disability artworks work to produce mediations of embodied, lived experience for their audiences. In other words, this kind of art takes the concept of disability, which we might otherwise experience *only* intellectually, or at a remove, and make that concept material, corporeal, and sensuous – creating an object which makes power relations more visible. This in turn opens an audience onto a condition of possibility. This is a powerful renunciation of the medical discourse of disability—where the afflicted individual is worked upon by the medical scientist, such that (s)he can be “fixed”—in favor of other methods of perceiving disability.

To examine these other perceptions of disability, I attempt to briefly sketch out the commonly held discourse of disability as seen in popular media, and I take up Michel Foucault’s notion of counter discourse, turning to the performance art group Sins Invalid and the artist Mat Fraser. Having undertaken this analysis of disability in art, by way of concluding my critical practice I turn to the creative. That is, my own creative practice, and the second half of my thesis, *Poesis/Prothesis: An Interactive, Experimental, Document of Disability*. This project seeks to extend its audience’s empathic understanding by explicitly intervening into the medical model of disability, and the problematic of disability simulation.

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CHAPTER 1

INTRODUCTION

With the recent passing (as of this writing) of Steven Hawking on March 14th, 2018, disability, it would seem, is having a moment. In discussions of his death, Dr. Hawking's disability looms large. Was he a genius despite his disability, or because of it? And how should the media responsibly talk about his disability, which figured prominently in his public persona?¹ Eventually of course, this discussion will subside, but only temporarily. These kinds of questions regularly return to our cultural discourse.

Granted, I am perhaps primed to notice such things not only as a disabled individual, but also as someone who makes art about disability. This art has its own perspective, informed in part by my experiences and exposure to theory, and in part by other, compelling artists. I have no qualms about the fact that my title transparently excerpts from Neil Marcus's play *Storm Reading*. The full quote reads: "Disability is not a brave struggle or 'courage in the face of adversity.' Disability is an art. It is an ingenious way to live."² Marcus proposes an alternative to the commonly accepted assumptions that so often surround disability; that it takes "courage," that it is a "struggle." I have chosen

¹ For a more in-depth consideration of Hawkins disability in the aftermath of his death, see Roy, Jessica. "Erasing Stephen Hawking's Disability Erases an Important Part of Who He Was." *Los Angeles Times*. March 16, 2018. Accessed March 20, 2018. <http://www.latimes.com/science/sciencenow/la-sci-sn-stephen-hawking-disability-rights-20180316-story.html>.

² *Storm Reading*. Directed by Rod Lathim. Performed by Neil Marcus, Matthew Ingersoll, and Kathryn Voice. New York: Access Theatres, 1996.
https://www.youtube.com/watch?time_continue=4415&v=dM9FLNM0MtA.

to quote him in my title so directly because I also wish to propose alternative imaginings of disability, using art as a medium. Examining the disabled body in relation to art offers an expanded field of possibility, one which speaks, in a descriptive fashion, to the largest possible demographic.

As disability activists are quick to point out, disability is a permeable category. Given the ever-expanding life expectancy of the general population, it is less a question of *if* one becomes disabled, and more a question of *when*. Secondly, and perhaps more importantly, art that deals explicitly with disability is very much interested in engaging the primary discourse of the body so prevalent in society and culture. As Tobin Siebers puts it in his introduction to *Disability Theory*, to engage disability from a critical standpoint is to "[transform] ... basic assumptions about identity, ideology, politics, meaning, social injustice and the body..."³ One of the critical interventions of disability studies, in other words, is a reformulation of the topologies surrounding the body. In turn, to understand art which engages disability, one must at least contend with disability studies.

Instead of a purely medical structure which places the "normal" body at its highest point, and the abnormal body at some inferior position below, disability studies reimagines "The Body" as a concept which exists along a possible continuum. This continuum allows for any number of neurological, biological, or genetic presentations. No one presentation is more "natural" than the next. Of course, the idea of normality doesn't exist in an oppositional sense. François Ewald points us to a notion of norms which reveal not simply a binary either/or relation, but rather an understanding of averages (which are fictions –

³ Siebers, Tobin. "Introduction." In *Disability Theory*, 1. Ann Arbor: University of Michigan Press, 2008.

impossible formulations), normalization, and the emergence of a bell curve.⁴ Still, both the bell curve and the binary logic it affords produce value laden judgments about the body and ability. Even as we understand that often work is undertaken to improve the norm—e.g, increase average life expectancy, lower “normal” infant mortality rates, etc. The larger point being, as we shall see, that for this kind of discourse, the body is a necessarily perfectible thing.

Nevertheless, as much as I agree with Tobin Siebers regarding the transformative capacity of disability, there is an important and specific intervention that I hope to apply to his logic. It centers itself around the fact that Siebers situates his book as working within an ideological vein and as such, his work in *Disability Theory* functions fundamentally as ideological critique. Siebers writes that “... ideology creates, by virtue of its exclusionary nature, social locations outside of itself...[Oppressed] social locations create identities and perspectives, embodiments and feelings, histories and experiences that stand outside of and offer valuable knowledge about powerful ideologies that seem to enclose us.”⁵ Note that if we follow from Ewald, the “abnormal” in the statistical sense, is *not* an excluded term. It helps to define the norm. Still, according to Siebers’ framework, disability is an “oppressed social location,” bundling together embodiment, experience, and affect. It is an explicit rejoinder to the idea that one cannot get “outside” of ideology. We also see a notion of “oppression” that continues to constitute a thread throughout much of disability studies and activism. Beyond an amorphous definition of the “social,” and its purview over a dense constellation of concepts, this ideological framework appears to cohere. As Siebers

⁴ Ewald, François. "Norms, Discipline, and the Law." *Representations*, no. 30 (1990): 138-61. doi:10.2307/2928449.

⁵ Siebers, Tobin. "Introduction." In *Disability Theory*, 8. Ann Arbor: University of Michigan Press, 2008.

continues to unpack disability as an “oppressed social location” however, limitations begin to appear.

Siebers writes, “...disability is not a pathological condition, only analyzable via individual psychology, but a social location complexly embodied. Identities, narratives, and experiences based on disability have the status of theory because they represent locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism.”⁶ On the one hand, Siebers is beginning to gesture towards a more specific notion of the social here. Disability and its related phenomena represent a social location because they are “locations and forms of embodiment.” Already, we can see a problem. Siebers has explained to us that ideology can be critiqued because it creates social locations outside of itself. Accepting this, it becomes imperative that we understand what a social location is. However, in defining what a social location is, Siebers says that a location is a location. This is circular logic, and there is a tertiary issue as well. Siebers states that these social locations allow “dominant ideologies of society [to] become visible and open to criticism.” What, fundamentally, is the point of this criticism? I am not being flippant here. I merely wish to draw our attention the fact that it is relatively easy to deconstruct the polarity of a presumed outside from which to offer critique. It is much harder to displace such a system entirely, as invoking the outside position only reinforces the system. Precisely because, I argue, this position is not really “outside” it.

Nevertheless, Siebers finds the answer in identity politics. He writes, “I offer no apology for [identity politics] because [it] remains in my view the most practical course of action by which to address social injustices against minority peoples and to apply the new

⁶Ibid., 14

ideas, narratives, and experiences discovered by them to the future of progressive, democratic society.⁷” Personally, I find nothing objectionable in this resuscitation and defense of identity politics. But, I would assert that his desire to “address social injustices against minority people and to apply the new ideas, narratives, and experiences discovered by them” to the future is not particularly or essentially ideological. More importantly, his defense of disability as an ideological concept is impaired (a deliberate word choice here) by the circular reasoning that a “social location” relies upon. Despite this, Siebers is by no means the only disability theorist to approach disability as an ideological construct. Consider this example from Jennifer Eisenhower:

the inclusion of disabled people doing art in art curriculum places an emphasis upon the representation of difference through a curriculum of admiration and appreciation in which individual artists are admired for their ability to create work similar to other able-bodied artists. In contrast, the discourse of the disability artist engages in a critical process of questioning the sociopolitical construction of disability and related ableist ideologies. Such work can include the expression of admiration and appreciation inherent to the construct of disabled people doing art while also introducing critical questions about the formation, maintenance, and possible disruption of ableist ideologies⁸

Functionally, what Eisenhower lays out here is a pedagogical analysis. Nevertheless, what she parses in this moment as “disabled people doing art” on the one hand, and the “disabled artist” on the other, is a turn towards ideological concerns. To be clear, I find this distinction between “artists with a disability” and “disabled artists” useful. Insofar as, following Eisenhower, the disabled artist is engaged in a “critical process of questioning the sociopolitical construction of disability.” In other words, the disabled artist is doing more

⁷ Ibid., 15

⁸ Eisenhower, Jennifer. "Just Looking and Staring Back: Challenging Ableism through Disability Performance Art." *Studies in Art Education* 49, no. 1 (Fall, 2007): 9. Accessed August 25, 2017. <http://www.jstor.org/stable/25475851>.

than simple mimesis. Or rather, if one were to put it in blunter terms: the disabled artist is not simply “admired for their ability to create similar work to [that of] other able-bodied artists.” In this context, the artist with a disability is being used, essentially, in a comparative fashion. They are held forth as a representative of a group. Several things are at issue here. Perhaps predominantly, used in this fashion, any given artist with a disability will, in some sense, become a metonym for the disability experience. That is, if an artist is held up in this comparative fashion, the audience might erroneously walk away with a falsely complete sense of knowledge of what it is like to live and work with a disability.

Veronica Wain speaks to the dangers of holding out a single disabled individual as an example of the group when she writes that despite there undoubtedly being a net positive to the prominence/awareness of disability experience in the public sphere, “... fragmentation from within has become more apparent. An autobiographical approach bears the risk of marginalizing the heterogeneous collective of the disabled community [which] has been instrumental in forging new ground in all spheres of life.”⁹ In contrast to the approach of the artist with a disability, which emphasizes the comparative and the metonymic, the disabled artist mines their own (that is, particular and situated) lived experience and narrative to put forth a coherent statement that is less susceptible to ideological blindness, precisely because it is acknowledged as particular and situated.

Having said all of this, however, I am drawn again to Eisenhower’s focus on “related ablest ideologies.” This is particularly prominent because just a few sentences earlier, Eisenhower highlights the “discourse of the disability artist.” For Eisenhower, I do not

⁹ Wain, Veronica. “Valorising Disability on Screen: When Did ‘Inspirational’ become a Dirty Word?”. In *Documentary and Disability*, edited by Catalin Brylla Helen Hughes, 43-59: Springer, 2017.

believe that this shift in terms is meant to signify a shift in focus. Rather, I contend that for all intents and purposes, what Eisenhower is outlining when she speaks to the “possible disruption of ablest ideologies,” is the utilization of a counter discourse, as Michel Foucault might term it.

Re-articulating Eisenhower and other disability theorists in this way accomplishes several things for me. On the one hand, it allows me to work with the unified calculus of terms. As I have said, Eisenhower herself uses the term discourse. However, if we set aside the practical/functional affiliations that Eisenhower has with discourse, we can see that one very effective move present in the desire to construct disability as ideological, is precisely the idea of disability. That is, if disability is ideological it is therefore conceptual, a feature of culture, and therefore, susceptible to paradigmatic shift. This is not to say that it is not useful as a starting point to consider disability as a conceptual object. As we shall see, it establishes a useful and productive foundation. However, it is functionally limiting, because it is abstract. By which I mean, more difficult to get at the material circumstances that underpin and hold the particular conceptualization and its work [in shaping social understanding and maintaining the status quo]. Fundamentally, the idea that the oppressed see power relations more clearly, as a singular concept, is an ideological critique. ideology critique may see things more clearly, but it does not thereby escape ideology. It remains within the terms set by the discourse.

Foucauldian discourse, on the other hand, allows us an expanded notion of disability that includes the corporeal as well as the metaphysical. That is, Foucault is also interested in interrogating the role of power in our society. Foucault writes, “Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders

it fragile and makes it possible to thwart it.”¹⁰ Here, Foucault sees power as a productive relation, one that creates possibility – including the possibility of “[rendering] it fragile.”

At the same time, we understand that ideological formations have ways of understanding power. Eisenhower very clearly engages a notion of power dynamics when she quotes Alan Sutherland’s analysis of politics and disability art: “We don’t see our disabilities as obstacles that we have to overcome before we try to make our way in the non-disabled cultural world. Our politics teach us that we are oppressed, not inferior.”¹¹

Eisenhower’s choice to quote Alan Sutherland is noteworthy because in this quote we have notions of oppression and inferiority, and therefore implicitly – notions of superiority and of dominance. Foucault however, deliberately positions himself outside of an understanding of power that operates primarily through oppression. And this is useful for the work of this essay. Foucault writes, “Power comes from below; that is, there is no binary and all-encompassing opposition between rulers and ruled at the root of power relations, and serving as a general matrix—no such duality extending from the top down and reacting on more and more limited groups to the very depths of the social body.”¹² This is not to say that the exercise of power is always peaceful. It can be violent. But, if we initially turned towards disability studies for a more expansive understanding of the body, we should turn towards Foucauldian discourse as it allows for a more expansive understanding of power. It is with this understanding of power that we can talk about the

¹⁰ Foucault, Michel. "Method." In *The History of Sexuality Volume 1*, 101. Reprint ed. New York: Vintage, 1990.

¹¹ Eisenhower, Jennifer. "Just Looking and Staring Back: Challenging Ableism through Disability Performance Art." *Studies in Art Education* 49, no. 1 (Fall, 2007): 10. Accessed August 25, 2017. <http://www.jstor.org/stable/25475851>.

¹²Foucault, Michel. "Method." In *The History of Sexuality Volume 1*, 94. Reprint ed. New York: Vintage, 1990.

various resistances to power as well as power itself. From Eisenhower's explication of the disabled artist, we understand that she is interested in engaging "ablest ideology." I would reframe that desire for my purposes as a desire to intervene in ablest discourse. With the understanding that at every point in which power is exercised, there is also the possibility of resistance.

When we talk about resistance in this way, what is being invoked is counter-discourse. Additionally, what is compelling about the idea of a counter-discourse as opposed to something like a demystification of ideological formation is precisely that a discourse is not a formation. Remember, Foucault states that power, that essential component of discourse, is not a structure. Rather, a discourse is a strategy, something which can be used. Power, as Foucault understands it, is an innervative and productive force. Discourse, in turn is intertwined with power. Therefore, it is useful to talk about disability art from within a context of Foucauldian counter discourse. To have an artistic practice is to produce an expressive object which, ideally, compels its viewer or audience. It is my contention that many disability artworks work to produce mediations of embodied, lived experience for their audiences. In other words, this kind of art takes the concept of disability, which we might otherwise experience *only* intellectually, or at a remove, and make that concept material, corporeal, and sensuous – creating an object which makes power relations more visible. This in turn opens its audience onto a condition of possibility.

To support this premise that disability art is material, not simply ideological, I must establish the commonly held discourse of disability in artistic media; the ways in which disability is discursively materialized, constituted, and organized. Additionally, I aim to

examine the counter discourses brought to bear by disabled artists as part of their artistic practices. I will look at the performance art group Sins Invalid, and the affiliated artist Mat Fraser, whose work actively excavates an agential and embodied understanding of disability. Such artists make the topic of disability, in some sense, material. They allow the audience to not just empathize with, but experience, disability.¹³ Finally, having examined these artists and the counter discourses they use – I will turn to my own attempts to utilize a counter discourse of disability through my creative practice in *Poetic/Prosthesis: An Interactive, Experimental, Document of Disability*.

¹³ I have chosen these specific artists and artistic projects because they each, in their own way, approach disability as bodily phenomena, which in turn allows the audience to experience disability as such.

CHAPTER 2

ON THE NECESSITY OF CHANGE

The Brain That Changed (2016) provides an example of the dominant discourses of disability¹⁴ In September 2016, a subsidiary of Australia's Special Broadcasting Service – SBS Viceland – posted it to their YouTube channel. The subject of the segment is neuroplasticity, or "the ability of the nervous system to form and reorganize connections and pathways, as during development and learning or following injury."¹⁵ As a method of examining this subject matter, *The Brain That Changed* uses one man – Andrew Short – as the focal point. Short has cerebral palsy. And if this segment is about neuroplasticity, it is also about Short himself. SBS Viceland describes the subject of the video in these terms: "Andrew Short, who lives with cerebral palsy, and his trainer Lee, are applying the concept of neuroplasticity – that the brain can change – to overcome his disability." Importantly, SBS Viceland positions Short's disability as something that can be – and ought to be – "overcome."

Certainly, Andrew himself shares this opinion. He says, "If you have a disability you need to do something about it..." and "you need to control your disability, or it will control you." These statements made by Andrew place this narrative firmly in a specific

¹⁴ SBS2Australia. "The Brain That Changed: Walking the Great Wall of China with Cerebral Palsy - The Feed." YouTube. September 22, 2016. Accessed October 06, 2017. <https://www.youtube.com/watch?v=0G4GMaxHuUQ>.

¹⁵ Oxford English Dictionary, "*Neuroplasticity*, *N.*" (Oxford University Press).

variety of disability discourse, one which promulgates the idea that disability is ultimately centered on the autonomous, but essentially burdened, individual. That with enough hard work, the effects of a disability can be mitigated, and perhaps even overcome. However, this track of transformation and change is rarely coded as emotively neutral. Often, this concept plays upon notions of pathos and of tragedy. I initially encountered this segment it was on Facebook, put out by a group called "TheBrave." ¹⁶ This group deliberately links notions of bravery to disability by showcasing Andrew's narrative in this way. He is made "Brave" by dealing with the consequences and lived reality of disability. What is highlighted here is essentially an adversarial relationship between the individual and the disability. Judging from the ongoing commentary feed and even the name of the group itself, what is emphasized and appreciated is the "inspiration" of Short. Here, the fact that he does not let his disability "control" him is continually praised, even as his physical regime to master his disability is shown to be a "battle."

Andrew Short's performance falls into the category of "Inspirationally Disadvantaged" cataloged by TVtropes.org. The website gives 40 unique examples of this trope from the years 1978 to 2017 – establishing this as one of the leading tropes of disability on television. ¹⁷ TVtropes writes, "... the Inspirational Disadvantaged Person superficially appears weak or downtrodden, but has hidden reserves of strength..." They then proceed to delineate several different types of Inspirational Disadvantaged Person. I would draw our attention to type B: "disparagingly known as the 'super-crip' by disabled

¹⁶"TheBrave." Facebook.com. September 26, 2017. Accessed October 06, 2017. <https://www.facebook.com/TheBraveProject/videos/1107623419324514/>.

¹⁷ "Inspirationally Disadvantaged." TV Tropes. May 1, 2013. Accessed October 06, 2017. <http://tvtropes.org/pmwiki/pmwiki.php/Main/InspirationallyDisadvantaged>.

people, there are characters with disabilities shown as going above and beyond the level of even nondisabled people in spite of their disabilities." Although a news segment, *The Brain That Changed* clearly extends the super-crip trope of the fictional examples summarized on TVtropes.

In the segment, Andrew and Lee engage in therapeutic activity. However, this activity is not couched in terms of therapy. At least, not in terms of institutional, traditional forms of therapy. Importantly, Viceland calls Lee Andrew's "trainer." This is at least in part, a pragmatic choice.¹⁸ That is, Lee, most likely does not have a degree in physical therapy, he calls himself a physical fitness trainer. However, the fact that Lee does not have a therapeutic license does not necessarily preclude Viceland from calling Lee a therapist as a descriptive label. Certainly, one could make the argument that because Andrew is engaging in therapy, under the direction of Lee, functionally, Lee is a therapist. The fact that Viceland calls Lee a trainer instead has implications beyond the pragmatic, however. It recalls a context of fitness, and perhaps even privilege. To have a physical fitness trainer is to afford to have a physical fitness trainer. Additionally, one of the voices of authority we see in this segment, upon seeing a video of Andrew flipping a tire, says that it looks like "boot camp." Remember, TVtropes emphasizes the Inspirational Disadvantaged Person's "hidden reserves of strength." With these specific emphases, the audience's understanding of this activity is pushed more towards a general sense of workout than "therapy." Added to all of this, in the video we the audience are told that Andrew and Lee go on "adventures," to various challenging sites that also have a valence of exoticism

¹⁸ Despite its specifically Australian point of origination, my initial encounter with this media was on Facebook. Because of this, it is not invariably tied to an "Australian" context, and is instead used here as an example of its genre.

and/or danger. Notably, Andrew's father David calls them "physically *challenges*" (4:55). This segment wants us, the audience, to understand these events as physical obstacles to be overcome. The photography that we then see of Andrew – in the Australian outback, overlooking the Sydney Opera House, becomes visible proof of success; and in both these images Andrew's arms are raised in triumph. These moments read as metaphorical trophies, or "inspirational" keepsakes. When Lee describes the Great Wall of China as the site of Andrew's next challenge – the inspirational quality of the image is magnified. At the time of this video, Andrew is/was still training for that trip. Still, the fact that Andrew is working to, and has worked to go to these places gives this narrative a kind of rarefied air. It is what makes Andrew, in this sense, a "super crip." This understanding of the way Andrew is portrayed here can only be solidified by the fact that amid all this static photography, Andrew is videoed sky diving (at 5:17).

Although the clip only lasts four seconds, its brevity does not detract from its intended purpose. The ability to skydive, which we see in motion here, is very much outside the reach of almost anyone. This functions as the proof, on the one hand, of Andrew's exceptionalism. Of course, the larger argument of the piece is that these achievements are possible due to neural plasticity, which extends beyond any single individual to the whole group. However, because Andrew Short's experiences are displayed, he becomes a focalizing point. As such, he is the Inspirational Disabled Individual, and the Inspirational Disabled Individual succeeds in the activities they do *in spite of* their disabilities. This wording gestures toward a specific understanding of disability. This is a discourse of disability, stretched to its farthest possible conclusion. That is, if the typical discourse of disability values the normal over the abnormal, then the extranormal – the kind of

inspirational ability and physical capacity that is gestured towards with the “super crip,” is valued that much more. In this way, normality becomes a locus of attention that cannot be ignored.

One of the intentions of this essay is to examine the ways in which disability is conveyed and represented socially and culturally in artistic media. It is my contention that disability as it is utilized in arguments to map and trouble the “normal” – that is, the normate – is always already embedded in discourse. Take, for example, the sequence which begins at 4:20 and ends at 4:55. It is the same sequence I referred to earlier, where Andrew states, “if you have a disability, you have to do something about it...” Returning to the sequence and examining it from this earlier point – we find not only that disability is something portrayed as mutable and open to change, but that at some point, Andrew considered suicide. And so, this sequence is working at dual purposes.

In addition to conveying a mode of medical discourse, this sequence is constructed in such a way as to convey to the audience the magnitude of suicide. When the camera shifts to a shallow focus, and rests on an aesthetically beautiful but fragile plant – the audience interprets that as a visual cue signifying the importance of what is being said on screen. The fragility of plant life is being equated to the unique qualities of a human life. The soundtrack shifts considerably with the audio becoming qualitatively somber. This works to draw the audience’s attention, and to cue an empathetic response. This empathetic cue attempts a kind of affective cue – but it primarily emphasizes the negativity of suicide, it does not produce different understandings.

Finally, the sequence ends on an extreme close-up of Andrew’s face, paired with Andrew’s voiceover, which completes the statement: “if you have a disability, you need to

do something about it or it will ruin you completely.” Viewed in its entirety, this segment is operating on a series of logics – both conceptual and visual – that attempt to construct a narrative whereby the individual overcomes his mental blocks as well as his physical ones. Andrew’s face, as it comes into focus, functions as a rejoinder or rebuke to the idea of suicide. This short sequence is the core of *The Brain That Changed*.

The visual constructions and choices on display – the art – serves to convey a specific message. That message is, to paraphrase Lee: “all of a sudden [he] doesn’t have a disability or dysfunction.” Andrew is the ultimate success story. He has overcome his disability, his *dysfunction*. This is the discourse of *The Brain That Changed*, that a disability can be mediated by medical science, and trained professionals, which is a key component of the medical model of disability as we shall see through Petra Kuppens, and she would most certainly agree that this news segment is part of the medical model of disability. However, the ultimate message of this piece is that the medical model of disability itself is mistaken, in so far as it was believed that the body cannot be trained or “fixed” beyond a certain point. Andrew’s story disproves this, and at the same time his story is meant to be emblematic. His exceptionalism is always in relation to the “normal.” That is, until he becomes normal enough to no longer be “dysfunctional.”

CHAPTER 3

[EN]COUNTERING MEDICINE

In her book *Studying Disability Arts and Culture: An Introduction*, Petra Kuppers writes about the two most dominant models of disability: the medical model of disability, and the social model. The medical model of disability is one that is highly individualized.

Kuppers writes that:

The medical model of disability is still dominant in many areas of social life. It describes disability as being lodged within a person. In the medical model view, the disabled person is disabled by their physical and mental condition. That condition is worked upon by medical scientists. the doctor locates what is 'aberrant,' abnormal, about the patient, and works toward normalizing the disabled person. The disability is here owned by the disabled person, and does not affect others. No one has to change what he, she, or ze does in response to the fact that someone who is different is among them. In this perspective on difference, there is a norm, a central style of being, and all have to align themselves with this norm, or risk being seen as "different."¹⁹

Kuppers locates what I perceive to be a central factor of the medical model of disability. She notes that "[a person's] condition is worked upon..." Labor, here, is essential. A person must work or be worked on to achieve the norm. If they do not, then they are othered. This is not to say that the average individual consciously excludes the disabled. But these are the conditions under which the "Disadvantaged Inspirational Person" exists.

Kuppers' critique, which many share, is "no one has to change what he, she, or ze does in response to the fact that someone who is different is among them." *The Brain that*

¹⁹ Kuppers, Petra. "Discourses of Disability." In *Studying Disability Arts and Culture: An Introduction*, 23-24. Palgrave Macmillan, 2014.

Changed will certainly submit to this critique, and I contend that this is one of the prominent reasons that the medical model of disability often, artistically, comes under attack. With this model, while people may seek to be understanding and compassionate, turning towards empathy, these external individuals are not implicated by the medical model of disability to the same degree as any given disabled individual. Within this structure, the average able-bodied individual is not expected to do anything to acknowledge and be responsive to the condition or category of disability. It is not their “problem” to do something about, even as this notion of “disability” works to define them as able-bodied.

For Kuppens, what is produced by the medical model of disability is a negative individualism, which in turn, is solved by accessing the “social” dimension. However, I am drawn to the ultimate message of *The Brain That Changed*, what we might call the ultimate reification of the medical model of disability. If Andrew Short is no longer functionally disabled – to follow Lee’s logic, what does that mean for the vision of humanity that this documentary projects? That is, using a Foucauldian discourse – it is not just Andrew who is perfectible. Rather, all bodies are perfectible. Which in turn suggests perhaps that all bodies should perfect themselves.

As a final point regarding the medical model of disability, it is manifestly important that Kuppens writes that in the medical model of disability, a disability does not “affect” others. This turn of phrase is both applicable and clever. She does not use “effect,” which has tones of evidential causality. She’s not interested in examining disability as part of a chain of relations that will ultimately have valences of blame, and thus responsibility. Instead, she is interested in highlighting and emphasizing affect. That is, the notion that people are (or are not, as is the case with this model) called to experience disability as a

matter of feeling and not merely cognition. As a part of artistic practice inherent to the disability art we are discussing, it is important to productively engage the affective register. The suicide sequence from *The Brain That Changed* attempts to be engage the affective register, but it's less than productive because it doesn't produce new understandings of suicide. Instead, it reduces the situation to an equation of blame and responsibility.

This is ultimately a goal, to build understanding across differing experiences. It is why I am wary of Eisenhower's artist with a disability. This is an artist who has a disability, and is valorized for the fact that he/she has a disability and makes art, not because he/she makes art that critically engages disability.

To be clear, it is not that there is no room in our society or culture for art that doesn't explicitly engage disability. Rather, it is simply that to compare the artist with a disability to their able-bodied peers, is essentially othering. That is, to valorize their art *simply and essentially* based on the fact that they are able to make art despite their disability, is othering; it reifies hierarchical divisions between the normal and the abnormal. Artistic practice as I understand it, should necessarily critique (and transform) the medical model of disability because disability, under the best of circumstances, operates affectively—that is, materially/corporeally/counter discursively—and therefore opens onto a condition of possibility. Kupperts acknowledges this condition of possibility in her reading of the social model of disability, which considers “particular forms of being human.” She writes:

...In the social model, disability appears in the interaction between the impaired person and the social environment. A disabled person has an impairment, such as short arms, blindness, an inability to read.... These impairments become a disability when these particular forms of being human encounter a society that favors design proportions that require long arms, visual communication, the written word.... From the perspective of the social model, for a woman using a

wheelchair, it is not her body or the wheelchair that disables her, but the architectural choice of stairs.²⁰

Here, I would call our attention to the fact that Koppers situates the moment of disability in the social model of disability as a moment of “encounter.” This moment of encounter is always in relation to society (i.e., that society privileges stairs to ramps for entering buildings, confronts those whose means of access requires ramps, and is impeded by stairs).

To reiterate, the social model is as compelling as it is to artistic practice because if the medical model ultimately positions disability as individualistic and operating within a clinical (in every sense of the word) and authoritative sense, the social model of disability expands this understanding – and allows us to think more relationally about disability.

Disability arises out of and is affected by community. This is not to say that the social model of disability does not have its critiques, especially as it relates to the lived reality of pain and discomfort that many people with disabilities face daily.²¹ For my purposes, however, what is represented by the social turn, is the recognition of the relational, affective capacity of disability. Paired with this notion of the affective however, are those situational and individuated markers of disability – the movements performed by Mat Fraser, as I will discuss²² – part exaggerated pantomime, part choreographed fight routine. Through his performance, the audience experiences something of what it is to inhabit his disability in the social world. Of course, I am interested in a relationality that extends beyond Fraser, or

²⁰ Koppers, Petra. "Discourses of Disability." In *Studying Disability Arts and Culture: An Introduction*, 26-27. Palgrave Macmillan, 2014.

²¹ For an overview of this critique, see Barnes, Colin. "Understanding the Social Model of Disability: Past, Present, and Future." In *Routledge Handbook of Disability Studies*, edited by Nick Watson, Alan Roulstone, and Carol Thomas, 12-29. London: Routledge, 2014.

²² *No Retreat, No Surrender*. Performed by Mat Fraser. Sin Invalid. 2009. Accessed December 8, 2017. http://www.sininvalid.org/video/pages/Mat_Fraser_2009.html.

any one individual. When speaking to disability in art, I am most interested in the ways that the disabled body implicates its audience. And so, before turning to Fraser completely, I want to consider the work of that *group* of disabled artists, to which he is affiliated, Sins Invalid.

CHAPTER 4

SLIPPERY NAMES, SEXY BODIES

Sins Invalid's full title is "Sins Invalid: An Unashamed Claim to Beauty in the Face of Invisibility" and their mission statement reads "Sins Invalid is a performance project on disability and sexuality that incubates and celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists as communities who have been historically marginalized from social discourse."²³

In these few short sentences, multiple notions are beginning to materialize, discursive formations are occurring. Sins Invalid explicitly contends with the nature of oppression. "Invisibility" and "Invalid"-ness each are rejected as synonyms for inferiority. How? To self-describe as "Invalid" is deliberately slippery rhetorical move; one which is resistant to singular understandings because "Invalid" as a word has multiple meanings dependent upon grammatical context and which syllable the speaker emphasizes.

On the one hand, per the OED,²⁴ in its nominal form, where the speaker emphasizes the first syllable, it refers to "an infirm or sickly person." In this understanding of the term, we see explicit linkages to the medical model of disability. The individual is disabled *because* he is sick, infirm. Granted, in today's sociocultural context, the use of a term like

²³ Sin Invalid. Sins Invalid | An Unashamed Claim to Beauty in the Face of Invisibility. Accessed December 09, 2017. <http://www.sinsinvalid.org/>.

²⁴ "invalid, adj.2 and n.". OED Online. June 2017. Oxford University Press. <http://www.oed.com/view/Entry/98893?rskey=xOILhH&result=2&isAdvanced=false> (accessed December 09, 2017).

“invalid” to describe disability is tonally anachronistic, to a point. As a culture we still comprehend what it is to be glossed as an invalid. And it is precisely because of this understanding – that this term is, in part, historically constituted, and has been used in an oppressive sense with relation to disability – that the intervention of self-description becomes apparent. The individuals involved in *Sins Invalid* gesture towards this historical understanding; by doing so, they re-articulate that which was oppressive to be self-affirming. In this action, I am reminded of Alan Sutherland’s gloss of disability politics, whereby Sutherland juxtaposes oppression and inferiority. Disability politics, and, I contend, disability art, is fundamentally centered around interventions into the logic of sociocultural oppression where the disabled body is deemed inferior. And *Sins Invalid*, and the projects it fosters, are a rejection of this mindset, and notably, a rejection of the secondary notion of “Invalid” in its adjectival sense, where the term means to be, quite simply, “not valid.”²⁵ At the same time, the OED goes on to explain that this use of the term also demarcates an object of “no power or strength.” To be “not valid” is to be inferior by any other name. While this instantiation of the term is not explicitly linked to disability, this adjectival sense of “invalid” remains a powerful component of the logic of sociocultural oppression, even as this logic may not operate consciously.

However, in Foucauldian terms, power operates within the condition of possibility. If *Sins Invalid*’s name rejects notions of inferiority and of invisibility, it engages in the formulation of possibility around claims to beauty and sexuality. In other words, *Sins Invalid* does more than simply critique oppression. Rather, they offer images and acts of

²⁵ "invalid, adj.1". OED Online. June 2017. Oxford University Press.
<http://www.oed.com/view/Entry/98892?rskey=lz1heN&result=1&isAdvanced=false> (accessed December 09, 2017).

possibility to their audience. Therefore, even as they do not explicitly define “discourse” from within a Foucauldian sense, whereby power is reified or thwarted, I assert that functionally what Sins Invalid performs is a counter-discourse.

Moreover, Sins Invalid’s particularized counter-discourse uses sexuality as a productive site of intervention and area of creative practice. Their subtitle, again, is “An Unashamed Claim to Beauty in the Face of Invisibility.” Here, we understand that at least in part, “Beauty” stands in as a euphemistic albeit “artistic” proxy for sex/sexuality; because sex is explicitly highlighted in the group’s mission statement, and it is an important, climactic thread in Mat Fraser’s piece. Certainly, this is not the only understanding of beauty that Sins Invalid references. On a purely aesthetic front, the disabled body can be understood as a transgressive object. Such a body, put simply, is automatically acknowledged to be ugly.²⁶

However, because they have “claim[ed]” it for themselves, the expanded possibility that Sins Invalid offers is precisely the sexual nuance. Mitchell S. Tepper points out that much of the public discourses surrounding disability and sexuality and its intersections focus on “deviance and inappropriate behavior,”²⁷ to the exclusion of pleasure and the possibility of eroticism. Sins Invalid’s work is, in part, a resuscitation of sexuality on the part of disabled individuals. Central to this work is the notion of an autonomous agency, wherein the disabled individual allows him- or herself to be conceived as a desirable object.

²⁶ Here I would draw attention to the fact that the group’s title also engages “Sin,” and by extension, a religious register, where the non-normative body is often, historically speaking, attributed to moral failings – a particular “ugliness.” In this way, we understand that the aesthetics of disability are always already contested and across contexts.

²⁷ Tepper, Mitchell S. “Sexuality and disability: The missing discourse of pleasure.” *Sexuality and disability* 18, no. 4 (2000): 283.

This notion of disability as something that allows for the possibility of desire tracks well with Foucault's analysis of sex. That is, if we understand that Foucault's discourse of sexuality operates based on repression. Repression is not about prohibition. Instead, repression operates by creating avenues of confession and management. Man becomes a "confessing animal."²⁸ Here, deviant—abnormal—thoughts and actions have positive value, they are interesting bits on which discourses of confession, self-improvement, pleasure, etc. go to work. Just as with homosexuality, disabled sexuality is something which can be performed, communicated, and spoken. *Sins Invalid* simply excavates this relation between sexuality and disability such that the connection between them is highlighted. Importantly, it is through the performance of these things that bodies and spaces can be managed. Even something as simple as the act of saying the group's name is a performance. The audience member will (most likely) be aware of the homographic nature of "Invalid," and by deliberately using that knowledge, *Sins Invalid* asks its audience to implicate themselves and (to begin) to recognize that these concepts are formed discursively. But what does the performance of disability itself look like? I am interested in the utility of performance art, specifically, as we consider the work of Mat Fraser. What he is doing on the space of a stage is very different from the way film or television works to convince its audience of its veridicality, or truthfulness.

²⁸ Foucault, Michel. "Scientia Sexualis." In *The History of Sexuality Volume 1*, 54. Reprint ed. New York: Vintage, 1990.

CHAPTER 5

MAT FRASER—ALTERNATIVES TO THE SUPER CRIP

I It is important, I think, to pay attention to Matt Fraser in his piece, *No Surrender, No Retreat*. Specifically, the ways in which he moves his body in that piece. As he bione hand, this is an operational intervention into the social discourse surrounding disability. That is, Fraser jabs, kicks, and dodges on stage, and we the audience understand that these movements are a response to the spoken word. It is a kind of kinetic catharsis to see the individual performer literally kicking as the spoken word track states, in an infantilizing fashion, “You are my hero of the day.” (at 0:38 seconds) And, “it is so good for my kids to have you as a disabled friend.” Notably, this last sentiment is repeated variably throughout the piece, via multiple speakers, who at times speak on top of one another. Here, the implicit social messaging that an individual with a disability confronts by existing in “the social” is externalized for the audience. This allows them to experience something of the psychological turmoil that this kind of messaging produces in the disabled body. And importantly, Mat Fraser’s body is disabled. Fraser has thalidomide-induced phocomelia; his upper extremities are visibly shortened and deformed. So, as Fraser kicks and punches – his physicality is emphasized doubly so. Not only is he physically responding to spoken words and phrases, but he is doing so with a non-normative body.

Additionally, as the spoken audio is layered throughout the piece, the individual sentiments expressed by the speakers tend to lose legibility, through delay, echo, and layering of sound. This is yet another way that the experience of disability is made material

and embodied. It is one thing to conceptually understand that disabled individuals are, at times, faced with a variety of condescending social interactions. It is a completely different kind of engagement to have that social interaction presented physically to the ear, and as a barrage.

And, it should be said, the sonic environment is presented to the audience through a specific and situated experience. We understand the performance of “You are my hero of the day” to be infantilizing because of the rising pitch of her voice (the speaker is presumably female) as well as the overall pace of her speech. It is from this infantilizing use of the word “hero,” that we can understand this piece, in part, operating as a rejoinder of sorts to the super Crip trope I critiqued earlier. What is being communicated in this instance is not a desire to be called a hero, but rather, a desire for such commentary to stop. Just as importantly, this desire is communicated through the audio, because we understand the idiosyncrasies of speech, and from Roland Barthes, we understand that speech is an embodied act.

Barthes is interested in the affective reality of the voice – that in hearing the voice we are compelled to experience it as a sensuous object. He contends that each voice has a “grain.”²⁹ Barthes will later go on to say that the grain of the voice is “the very precise space of the encounter between a language and a voice.”³⁰ Barthes uses “encounter” to describe a “precise space.” As applied to Matt Fraser’s work though, we understand encounter to be performed on stage; it occurs in a particular space. To borrow from Barthes,

²⁹ Barthes, Roland. “The Grain of the Voice.” *Image, Music, Text*, translated by Stephen Heath, Hill and Wang, 2009, p. 181

³⁰ *Ibid.*,

that space is “precise,” insofar as every performance is informed by its space. What Barthes is gesturing towards is an understanding of the performative.

Fraser is using his body to materialize his experience. Beyond his body, the other salient devices are the various voices, narrating different perspectives in relation to Fraser’s body. The voices do more than relate information. The audience is invited to contemplate the place that Fraser occupies in society. If disability offers the opportunity to consider an expansion of possibility, it is through the voices of this piece that we come to experience disability.

Importantly, the piece is titled *No Surrender, No Retreat*. Because the spoken track is omnipresent throughout the piece, the audience makes an associative connection between the dialogue and the fight-like choreography. Added to this, the vocabulary of Fraser’s title is connotatively martial. “Surrender” and “retreat” are words used in relation to war. Here, Fraser has engaged in a register of resistance. In fact, he, through choreography, is actively resisting and is ultimately beaten down to the ground.

This choreography is highly reminiscent of a boxing match, with intricate footwork, ducking and jabbing. Because of Fraser’s physicality, one could even assume that the various roundhouse kicks on display is a version of a boxing punch. The final element of choreography occurs at the end, and it is what solidifies my analogy of a boxing fight. Another individual comes on stage, and drags Fraser out of frame, by his shoulders, exactly as one would a downed comrade. In the space that Fraser has constructed here, he has lost the fight. But, in losing the fight, Fraser also implicates his audience. They hear this barrage of condescending and/or outright bigoted speech at the same time as they see Fraser’s body being pushed to the floor. Speech as presented here is made material not only because it is

relentless – that is, ongoing—but because it causes Fraser’s body to change. In that sense of the word, it is a force. And, because the speech loses its legibility periodically, it is something the body, through the ear at least, cannot understand. Here, Fraser presents an understanding of his social world to the audience that they cannot misconstrue, and this is done through a performance of the body and the voice.

Additionally, it is through the voice that Fraser engages multiple conceptions of the sexual, that particular realm of Sins Invalid. The spoken word track, which functions as a metonym for the larger social world, alternatively refers to the act of copulation as “making love,” “the act of reproduction,” and “fucking.” What is evidenced here is the move across social registers, from the euphemistic to the profane. At the same time, the devaluation of the disabled body moves from implicit to explicit as the contextual statements surrounding these sexual acts shift from the interrogative – “do you need help making love?” – to the declarative – “I would never fuck a cripple.” Functionally, these kinds of statements are distillations and types. They are themselves, embodiments and lived perspectives, even as Fraser uses these sentiments to demonstrate and perform a lived perspective as a disabled artist. These sentences come from individual people.

Additionally, one should note that in detailing the sexual, Fraser is evoking a discourse of pleasure. That is, one “makes love” or “fucks” for reasons beyond a desire to reproduce. This is a moment that reads clearly as interventionist. The narration states: “Reproduction is a mistake. Another deformity would be a disaster.” Sex would be a “mistake” because by involving the disabled body, there is always the possibility that a disabled child would be born. In the piece, the social voice positions this as a negative. As an audience, we clearly recognize that Fraser’s performance enacts a critique. That is, it is

a bigoted opinion that to have sex with someone who has a disability is inherently wrong. Moreover, Fraser (and by extension, *Sins Invalid*) is putting forth an alternative discourse here, a discourse that eroticizes the disabled body, and offers it as something to be desired.

It is a question of artistic desire that I wish to pick up next. I have explored dominant discourses of disability and counter discourses of disability which use materiality and sexuality to affect their audience, to shift their understanding of what disability is. As an artist, I am also interested in shifting my audience's understanding of disability into a more productive frame. I attempt to do so in a web-based project, *Poetic/Prosthesis: An Interactive, Experimental, Document of Disability*.³¹

³¹ See Appendix B

CHAPTER 6

CREATING POETICAL SIMULATION

Unlike Mat Fraser and *Sins Invalid*, the site of my intervention into disability discourse is not centered around sexuality. Rather, I am interested in creating more empathetic versions of disability simulation. Disability simulation is any activity which seeks to emulate the physical experience of disability for someone who is not disabled. These activities tend to be short-term, transpiring/taking place/occurring over the course of a class period or day, with the goal of expanding the participant's empathy for the disabled. Unfortunately, as many studies³² have pointed out, these simulations have a tendency to backfire. Instead of creating a sense of empathy on the part of the participants, they can just as easily evoke feelings of pity. I believe that, in theory, disability simulation can be a positive strategy. It would allow for any participant³³ to viscerally realize the various aspects of daily life that a disabled individual must contend with that they, as an able-bodied individual, can often forgo. Ideally, it would maximize the potential of an empathetic impulse, and minimize the potential recourse to pity.

My project exists as a website which uses audio, visual, and interactive elements to immerse the participant in a particular, situated, experience of disability. That is, my

³² See Burgstahler, Sheryl, and Tanis Doe. "Disability-related simulations: If, when, and how to use them in professional development." *Review of Disability Studies: An International Journal* 1, no. 2 (2014). For an overview of some of the common conceptual/methodological issues surrounding disability simulations.

³³ I consciously use the term "participant" throughout this section, as this is the vernacular of disability simulation.

experiences as an individual with cerebral palsy. I am aware that my experience of disability is not a universal experience of disability. However, one of the pitfalls of the traditional disability simulation activity is how broad it attempts to be. By grounding this project in the autobiographical, it becomes easier to structure – with a definite beginning and ending, and markers of disability become easier to construct. Additionally, I address the participant throughout this experience as “you.” This allows for a more direct, intimate, relationship between the participant and the on-screen narration. The use of “you” also affectively hails the participant, obliging them (on some level) to respond.

In terms of the various markers of disability themselves, I utilize a chat bot to emulate the experience of occupational therapy for me. By situating it within the digital confines of a chat box/bot, I can impute something of the repetitious nature of that activity onto the participant. In their possible frustration, they may realize something of what it is to have to engage in occupational therapy. Another scenario involves the utilization of the computer mouse to click on screen to clean their hands, and clear away the red bubbles – which represent blood.

In the project, I spent so much time on hands due to several factors. Namely, it is a locus through which I experience/ed much of my disability and at the same time, I am interested in the notion of the digital. That is, “digital” can alternatively refer to qualities relating to the digits of a hand, as well as “digital” online environments. Ultimately, the main goal with this project was to remind the participants that they inhabit a body, even as they use a networked node – the computer. It is not uncommon for an able-bodied individual to primarily notice their bodies when something goes wrong.

In my pursuit of drawing attention to corporeality, I deliberately utilized an aesthetic of “glitchy,” or tactile, images and manipulated audio. In her book *Touch: Sensuous Theory and Multisensory Media*, Laura Marks states, “in haptic visuality, the eyes themselves function like organs of touch.”³⁴ Here again, we see a repetition of the digital. As an artist, I wanted the eyes to grasp on to things, because often, I do not have the ability to physically grasp. Relatedly, Marks says of the web: “surfing most [websites]... I am not sure how it opens us to the unknown – except perhaps for those moments when, waiting for download, we notice the shape of our fingernails for the first time.”³⁵ Here, when Marks recalls the “unknown,” I would gloss this moment as her calling attention to the fact that it is occasionally good to defamiliarize oneself, and be reminded of what she will shortly go on to call a “shared physical existence.” This is, in different terminology, is what I am attempting to do.

Thus, I have deliberately made the participant “[wait] for a download.” The website can be jarring. Some webpages are jarringly pink, and the graphics are not always sleek – in fact, they call attention to themselves. I am certainly not the first artist to do this kind of work. Curt Cloninger and Ben Coonley, each in his own way, also valorize an aesthetic of roughness. All this is to say that I am aware as an artist I am working in established modes. However, my specific intervention centers around the valorization of the body. My project engages concepts of the digital – the title explicitly highlights prosthesis – a term most commonly associated with disability, but one which could also be applied to networks and the digital, as being an extension of the self. All of this is in the service of reminding the

³⁴Marks, Laura U. "Introduction." In *Touch: Sensuous Theory and Multisensory Media*, 2. Minneapolis: University of Minnesota Press, 2002.

³⁵ Ibid. Xii

participant that their body still exists. Perhaps just as importantly, my project engages in institutional voice – which says that a body must be trained, mediated, and managed.

Ultimately, this is a discourse that I hope to transform productively from within. What does it mean to be trained as a Person with a Disability? What does such a body do? In the face of such questions, any participant should be able to come to some sort of answer. Ultimately, I cannot dictate a participant's response. But, at its base, a marker of success for me would be to never hear the phrase – “that was brave...”

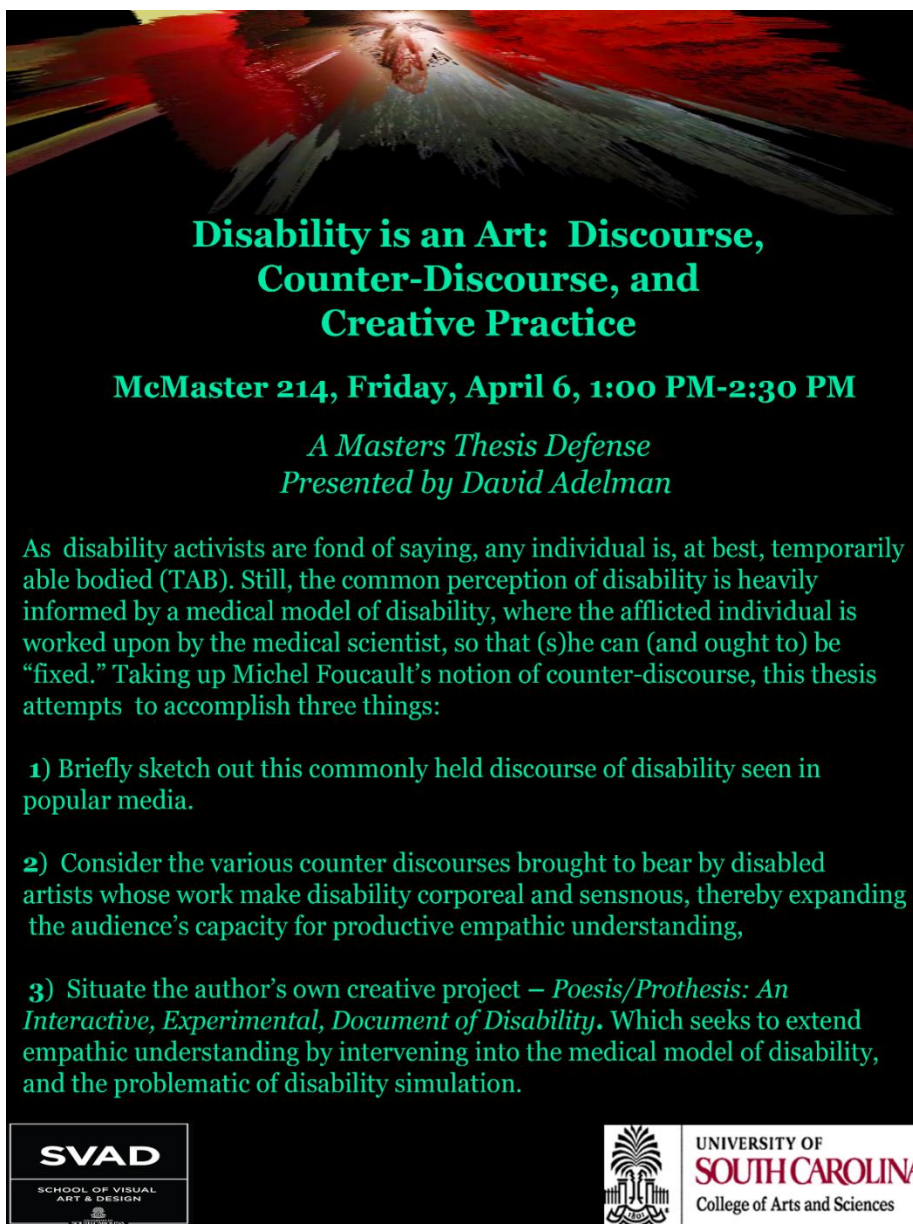
BIBLIOGRAPHY

- Barnes, Colin. "Understanding the Social Model of Disability: Past, Present, and Future." In *Routledge Handbook of Disability Studies*, edited by Nick Watson, Alan Roulstone, and Carol Thomas, 12-29. London: Routledge, 2014.
- Barthes, Roland. "The Grain of the Voice." *Image, Music, Text*, translated by Stephen Heath, Hill and Wang, 2009, p. 181
- Burgstahler, Sheryl, and Tanis Doe. "Disability-related simulations: If, when, and how to use them in professional development." *Review of Disability Studies: An International Journal* 1, no. 2 (2014).
- Eisenhauer, Jennifer. "Just Looking and Staring Back: Challenging Ableism through Disability Performance Art." *Studies in Art Education* 49, no. 1 (2007): 7-22.
- Ewald, François. "Norms, Discipline, and the Law." *Representations*, no. 30 (1990): 138-61. doi:10.2307/2928449.
- Foucault, Michel. "Method." In *The History of Sexuality Volume 1*, 94-101. Reprint ed. New York: Vintage, 1990.
- Foucault, Michel. "Scientia Sexualis." In *The History of Sexuality Volume 1*, 54. Reprint ed. New York: Vintage, 1990.
- "Inspirationally Disadvantaged." TV Tropes. May 1, 2013. Accessed October 06, 2017. <http://tvtropes.org/pmwiki/pmwiki.php/Main/InspirationallyDisadvantaged>.
- "invalid, adj.1". OED Online. June 2017. Oxford University Press. <http://www.oed.com/view/Entry/98892?rskey=lz1heN&result=1&isAdvanced=false> (accessed December 09, 2017)

- "invalid, adj.2 and n.". OED Online. June 2017. Oxford University Press.
<http://www.oed.com/view/Entry/98893?rskey=xOILhH&result=2&isAdvanced=false> (accessed December 09, 2017).
- Marks, Laura U. "Introduction." In *Touch: Sensuous Theory and Multisensory Media*, xii-2. Minneapolis: University of Minnesota Press, 2002.
- Kuppers, Petra. "Discourses of Disability." In *Studying Disability Arts and Culture: An Introduction*, 23-27. Palgrave Macmillan, 2014.
- No Retreat, No Surrender*. Performed by Mat Fraser. Sin Invalid. 2009. Accessed December 8, 2017. http://www.sinsinvalid.org/video/pages/Mat_Fraser_2009.html.
- Oxford English Dictionary, "*Neuroplasticity, N.*" (Oxford University Press)
- Roy, Jessica. "Erasing Stephen Hawking's Disability Erases an Important Part of Who He Was." Los Angeles Times. March 16, 2018. Accessed March 20, 2018.
<http://www.latimes.com/science/sciencenow/la-sci-sn-stephen-hawking-disability-rights-20180316-story.html>.
- SBS2Australia. "The Brain That Changed: Walking the Great Wall of China with Cerebral Palsy - The Feed." YouTube. September 22, 2016. Accessed October 06, 2017. <https://www.youtube.com/watch?v=0G4GMaxHuUQ>.
- Siebers, Tobin. "Introduction." In *Disability Theory*, 8-15. Ann Arbor: University of Michigan Press, 2008.
- Sins Invalid. Sins Invalid | An Unashamed Claim to Beauty in the Face of Invisibility. Accessed December 09, 2017. <http://www.sinsinvalid.org/>.
- Storm Reading*. Directed by Rod Lathim. Performed by Neil Marcus, Matthew Ingersoll, and Kathryn Voice. New York: Access Theatres, 1996.
https://www.youtube.com/watch?time_continue=4415&v=dM9FLNM0MtA.
- "TheBrave." Facebook.com. September 26, 2017. Accessed October 06, 2017.
<https://www.facebook.com/TheBraveProject/videos/1107623419324514/>
- Wain, Veronica. "Valorising Disability on Screen: When Did 'Inspirational' become a Dirty Word?". In *Documentary and Disability*, edited by Catalin Brylla Helen Hughes, 43-59: Springer, 2017.

APPENDIX A

THESIS DEFENSE FLYER



**Disability is an Art: Discourse,
Counter-Discourse, and
Creative Practice**


McMaster 214, Friday, April 6, 1:00 PM-2:30 PM

*A Masters Thesis Defense
Presented by David Adelman*

As disability activists are fond of saying, any individual is, at best, temporarily able bodied (TAB). Still, the common perception of disability is heavily informed by a medical model of disability, where the afflicted individual is worked upon by the medical scientist, so that (s)he can (and ought to) be “fixed.” Taking up Michel Foucault’s notion of counter-discourse, this thesis attempts to accomplish three things:

- 1) Briefly sketch out this commonly held discourse of disability seen in popular media.
- 2) Consider the various counter discourses brought to bear by disabled artists whose work make disability corporeal and sensuous, thereby expanding the audience’s capacity for productive empathic understanding,
- 3) Situate the author’s own creative project – *Poesis/Prothesis: An Interactive, Experimental, Document of Disability*. Which seeks to extend empathic understanding by intervening into the medical model of disability, and the problematic of disability simulation.

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SOUTH CAROLINA
College of Arts and Sciences

APPENDIX B

CREATIVE PRACTICE

The URL for the creative portion of this thesis is <http://poeticprosthesis.com/index.html>

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